Transition of Autism from childhood to adulthood

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Presentation to Association for Child Neurodevelopmental Disorder, Sweden
13 of March (10.15 -12.00 a.m), Stockholm, Sweden.

UNIVERSITY OF LEICESTER

Overview of presentation

- **Defined**... eligibility criteria for support
- **Issues**, life course stage, intersections with institutional procedures and requirements, autism specific vulnerabilities, psychological development, Comorbidity, costs, effectiveness of transition support
- A mark of our information gaps in autism – its all about childhood and **neglect of adulthood** but ... hence the need to look at what little we know about adulthood
- Starting with **epidemiology** then access to **diagnosis** (transition history and effects of failed early recognition)
- Then post diagnosis **care**

Transition defined...

- Lack of widely (internationally) agreed definition even in the most widely cited context transition to adulthood;
- **Inclusion and exclusion criteria** from a trial protocol:

1. Adolescents diagnosed with Autism spectrum disorder, as defined by the diagnostic and statistical manual of mental disorders, fifth edition (DSM-5) or the fourth edition (DSM-4);
2. Living in [defined geographic area];
3. Able to read and write in English at a year five reading level;
4. Enrolled in years 8–11 at school (including mainstream, special education or home-schooling programs);...

Impact of autism differences

- **Autism implies:**
- Rigidity, preference for routine, repetitive behaviours and intolerance to change
- **Difficulties with:**
- socialisation (the 'social instinct') and with the social aspects of communication;
- including difficulties starting and maintaining relationships (keeping in touch with childhood friends);
- conceptualizing hypothetical future events and other developmental delays.
- Elevated risk of **comorbidities** of relevance such as **ADHD**, **Intellectual Disability**, epilepsy, anxiety,
- Issues raised by reliance and **dependence** on others (transition and reduced parental contact)
- **Reliance on services that are designed for a specific age group (child to adult, adult to older age)**
- Parallel *psychological developmental issues* on which transition demands may impinge
- (NB differentiate known and already diagnosed from unrecognised autism).

Life course and the range of possible transitions

- Entry to first school, leaving the home of one's infancy;
- Change from junior to senior school;
- **From school to College or to employment (NB eligibility criteria for transition support);**
- Leaving the childhood home;
- Moving home (at any time)
- Beginning a partnership (moving in with a partner; separating);
- Arrival of children, becoming a parent, becoming a parent of teenagers and older children, the empty nest;
- Move to a different employer – change of routine in a job;
- Ending employment to retire – loss of routine, social contact;
- Loss of partner;
- Loosing independence in late life – moving to a care home.

Transition Planning Overview

- Current transition planning practices have resulted in **inferior outcomes** for adolescents on the autism spectrum when compared to adolescents with other disabilities;
- Only **23%** of adolescents with autism are involved in transition planning;
- even when they are involved, they are less likely to be **active participants** in the process.
- Fewer parents of adolescents with autism perceive the transition planning process as useful and have reported that they want to be more involved in the process;
- Currently, schools tend to focus on the academic performance of adolescents on the autism spectrum who do not have an Intellectual Disability, rather than engaging them in comprehensive transition planning;
- In addition, autism-specific challenges are often not taken into consideration;
- Difficulties in gestalt processing (central coherence) and abstract thinking, adolescents on the autism spectrum benefit from support to understand the 'big picture', and why they need to get a job after school.

- Child Adolesc Psychiatry Ment Health. 2016; 10: 48. Published online 2016 Dec 28. doi: 10.1186/s13034-016-0137-0. PMCID: PMC5192743. Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: trial protocol. Megan Hatfield,corresponding author1,2 Marita Falkmer,1,2,5 Torbjorn Falkmer,1,2,3,4 and Marina Ciccarelli 1,2

Research Evidence

- Substantially dominated by **US literature** (and the transition from school and well supported child services to adult life and almost no services);
- Evidence from studies of transition experiences;
- Issues around **transition planning** (preparedness) and services or lack of them;
- *Effectiveness* evaluations of transition support technologies, interventions, support?
- **Effectiveness trials proposed and underway**
- Studies of support into employment may be seen as supporting transition
- Small pilots of transition planning and support;
- Evidence of *outcomes* using child autism cohorts, e.g. Rutter, Howlin cohort, which represent early identified child outcomes;
- And using child *population cohort*(s) e.g. Utah cohort;
- Transitions tracked using national registers.

Epidemiology of ASD

- Childhood (Fombonne, McGill, Montreal)
- Adulthood
- Global Burden of Diseases.
- Methods in community surveys and using populations registers
- Proportion of cases in surveys know and identified
- Surveillance and case register data (in the absence of further data collection)
- Characteristics of the population
- Transition planning in the reality of delayed recognition

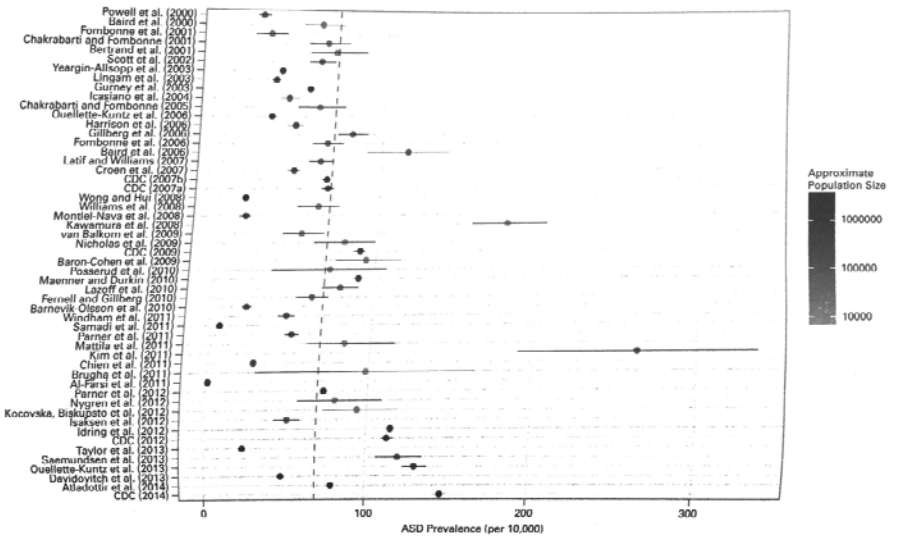


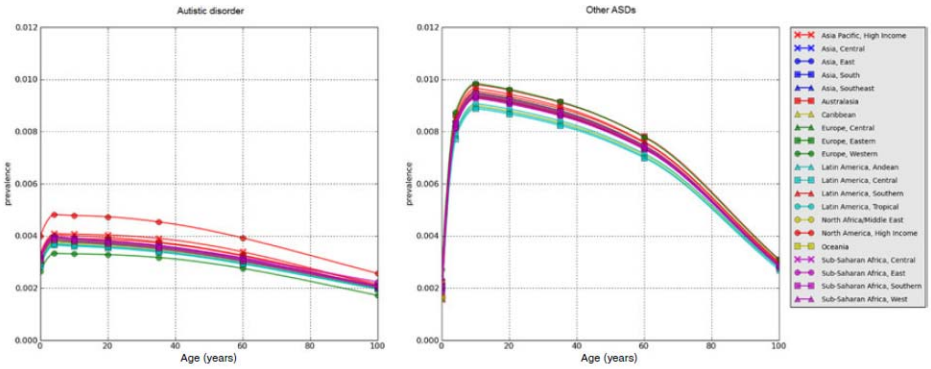
FIGURE 12.2 Prevalence estimates for autism spectrum disorder since 2000 (per 10,000 with 95% confidence intervals; also see Figure 12.4). The dashed vertical line denotes the mean prevalence of 59/10,000 across all 53 surveys.

Presmanes Hill, Zuckerman, Fombonne, Epidemiology of Autism Spectrum Disorder, in Autism Spectrum Disorder, McDougle, 2016, OUP.

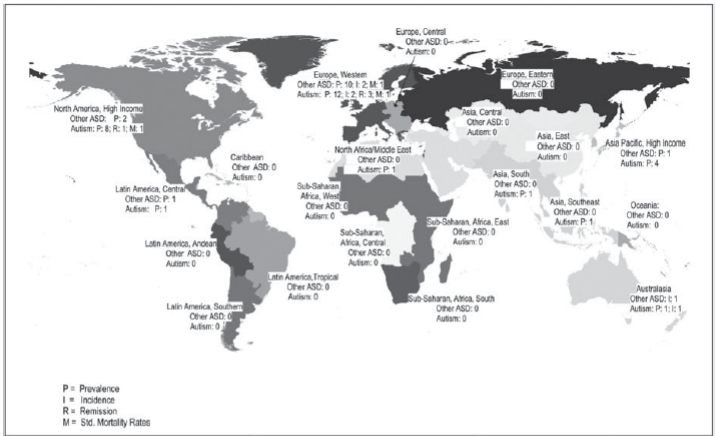
Global Burden of Disease - DISMOD

- **Background**. Autism spectrum disorders (ASDs) are persistent disabling neurodevelopmental disorders clinically evident from early childhood. For the first time, the burden of ASDs has been estimated for the Global Burden of Disease Study 2010 (GBD 2010). The aims of this study were to develop global and regional **prevalence models** and estimate the global burden of disease of ASDs.
- **Method**. A systematic review was conducted for epidemiological data (prevalence, incidence, remission and mortality risk) of autistic disorder and other ASDs. Data were pooled using a **Bayesian meta-regression** approach while adjusting for between-study variance to derive prevalence models. Burden was calculated in terms of **years lived with disability (YLDs)** and **disability-adjusted life-years (DALYs)**, which are reported here by world region for **1990 and 2010**.
- **Results**. In 2010 there were an estimated 52 million cases of ASDs, equating to a prevalence of 7.6 per 1000 or **one in 132 persons**. After accounting for methodological variations, there was **no clear evidence of a change in prevalence** for autistic disorder or other ASDs **between 1990 and 2010**. Worldwide, there was little regional variation in the prevalence of ASDs. Globally, autistic disorders accounted for more than 58 DALYs per 100000 population and other ASDs accounted for 53 DALYs per 100000.
- **Conclusions**. ASDs account for substantial health loss across the lifespan. Understanding the burden of ASDs is essential for effective policy making. An accurate epidemiological description of ASDs is needed to inform public health policy and to plan for education, housing and financial support services.
- A. J. Baxter1,2*, T. S. Brugha3, H. E. Erskine1,2, R.W. Scheurer2, T. Vos1,4 and J. G. Scott2,5,6 The epidemiology and global burden of autism spectrum disorders. Psychological Medicine, Page 1 of 13. © Cambridge University Press 2014 doi:10.1017/S003329171400172X

Global Burden of Disease - DISMOD



Estimated point prevalence of autistic disorder and other autism spectrum disorders (ASD) for males in 2010, by Global Burden of Disease (GBD 2010) world region.



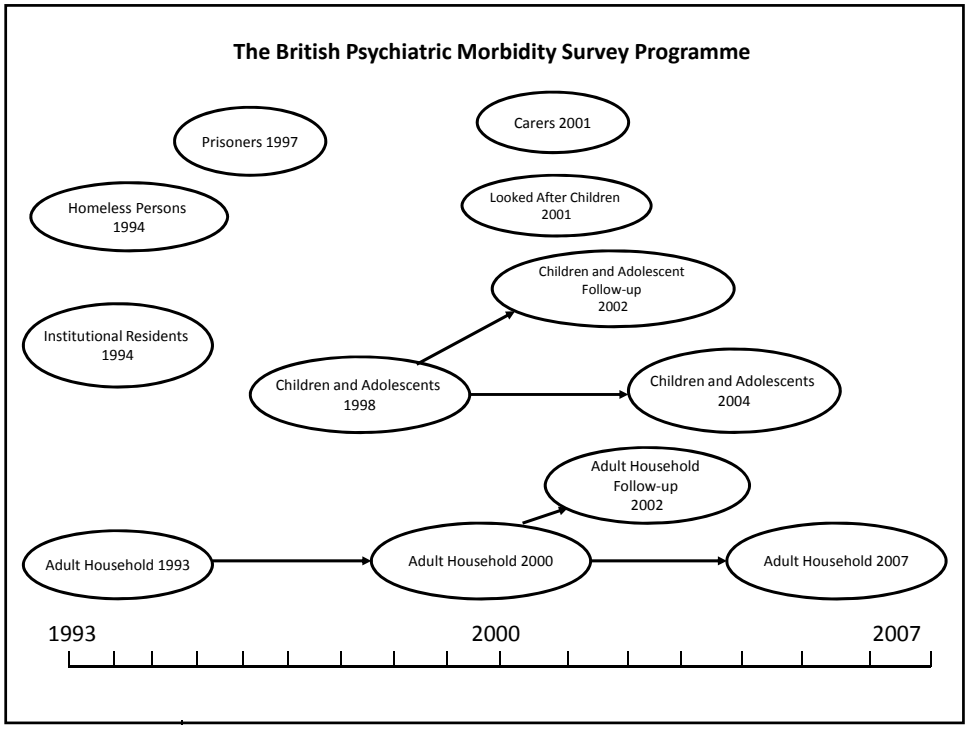
	Autism		Asperger's disorder	
Empirical data	No. of studies (datapoints)	No. of regions (countries)	No. of studies (datapoints)	No. of regions (countries)
Prevalence	27 (73)	8 (16)	13 (23)	4 (8)
Incidence	3 (6)	2 (3)	3 (10)	2 (3)
Remission	4 (4)	2 (3)	1 (1)	1 (1)
Excess mortality	2 (10)	2 (2)	1 (1)	1 (1)

Development of adult epidemiology methodology for autism

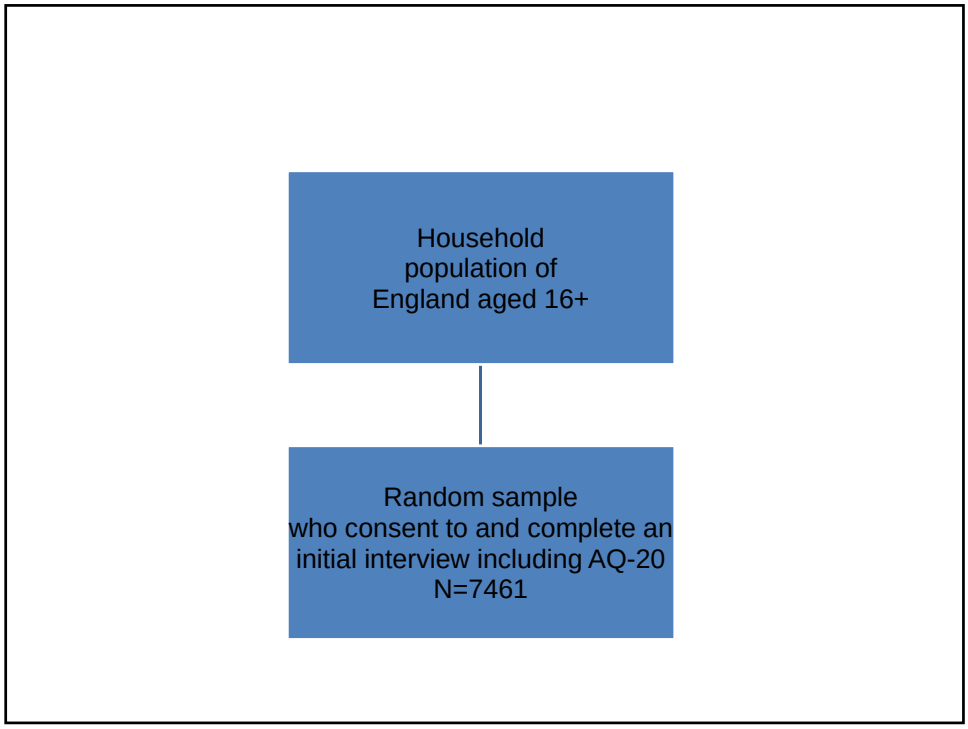
- No adult epidemiological studies to go by
- Adults with the condition unlikely to know they have it and often unaware of what makes them different
- Epidemiological methods to date dependent on collecting information on childhood development from parents / similar observers such as teachers
- Clinician diagnoses are highly unreliable...

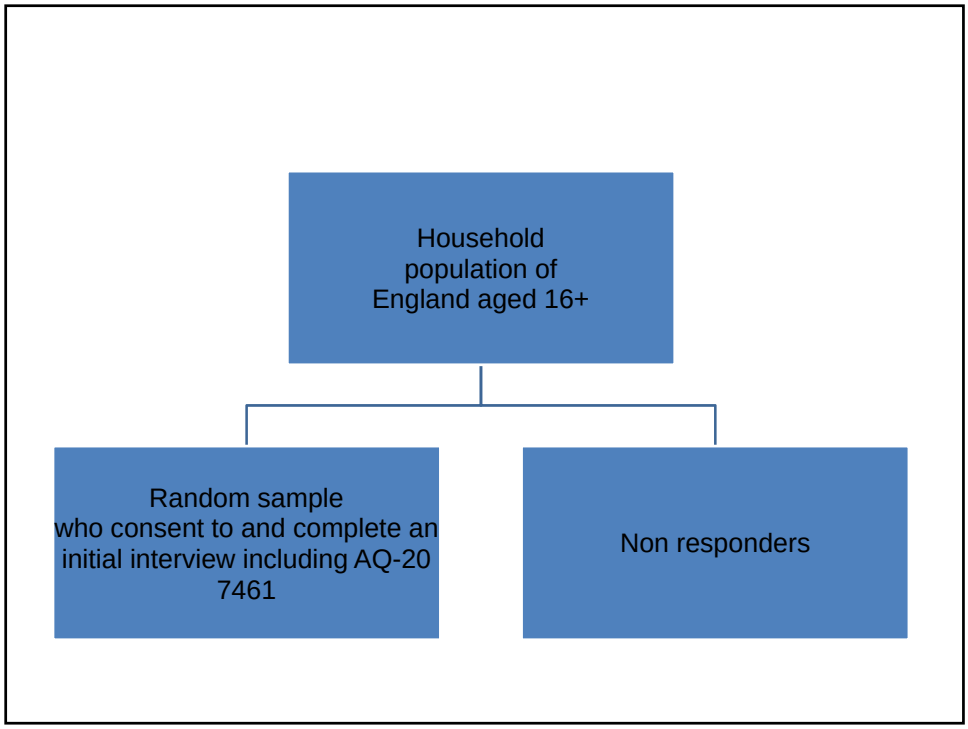
Our study aims were to:

- Conduct an efficient two-phase survey of ASD
  - as well as psychosis and personality disorder within a third Adult Psychiatric Morbidity Survey (APMS 2007)
- Maximise the exclusion of low scoring cases
  - for accurate prevalence estimation
- Maximise the overall number of cases found
  - for further sub-group analysis, for example to study associations with ASD in an unbiased sample



Household population of England aged 16+


Household population of England aged 16+
Random sample who consent to and complete an initial interview including AQ-20 N=7461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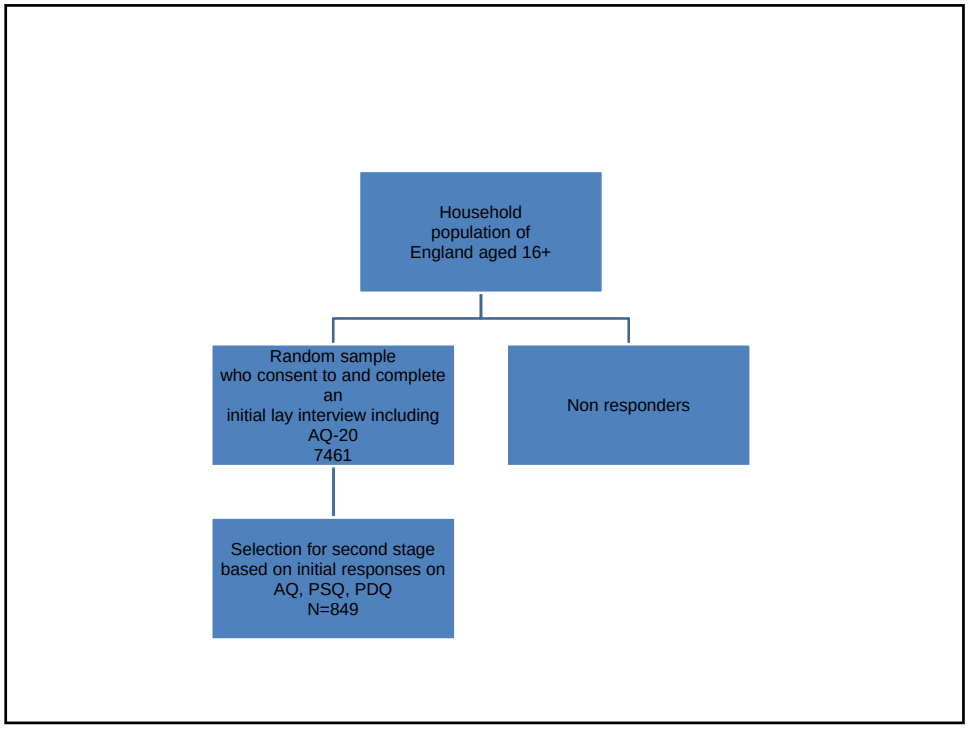
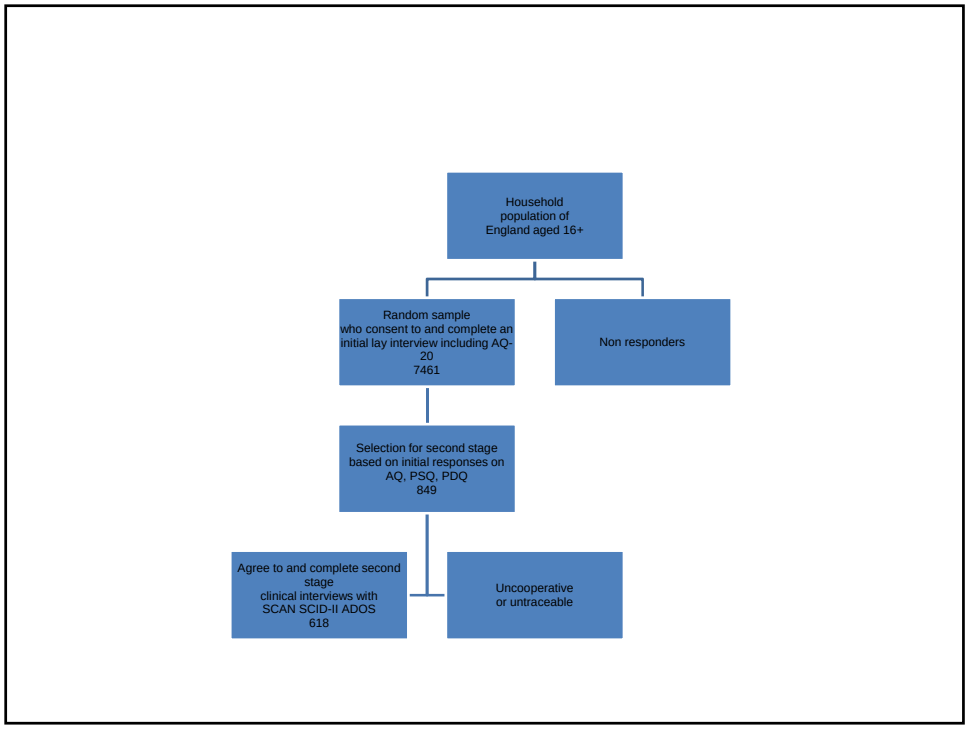
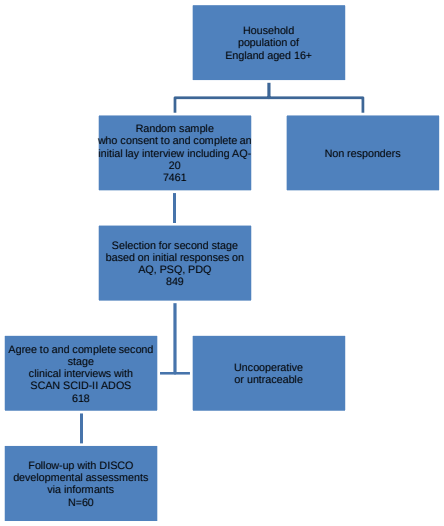
Non responders


Household population of England aged 16+
Random sample who consent to and complete an initial lay interview including AQ-20 7461
Non responders
Selection for second stage based on initial responses on AQ, PSQ, PDQ N=849


Household population of England aged 16+
Random sample who consent to and complete an initial lay interview including AQ-20 7461
Non responders
Selection for second stage based on initial responses on AQ, PSQ, PDQ 849
Agree to and complete second stage clinical interviews with SCAN SCID-II ADOS 618
Uncooperative or untraceable



Criteria at phase one for selecting for phase two:

1. Diagnosis
2. Treatment
3. Symptoms

Psychosis…

Criteria at phase one

1. Diagnosis - high
2. Treatment - likely
3. Symptoms - validated screening tools

The above criteria have been fairly successful in studying the epidemiology of psychosis in the community

Psychosis…

Criteria at phase one

1. Diagnosis - high
2. Treatment - likely
3. Symptoms - validated screening tools

- 313 participants met 1+ criteria
- All potential 'cases' selected for phase two

Autism spectrum disorder…

Criteria at phase one

1. Diagnosis - low
2. Treatment - unlikely
3. Symptoms - screening tools not validated in gen pop

Navigating in the dark....

Phase one ASD screening tool

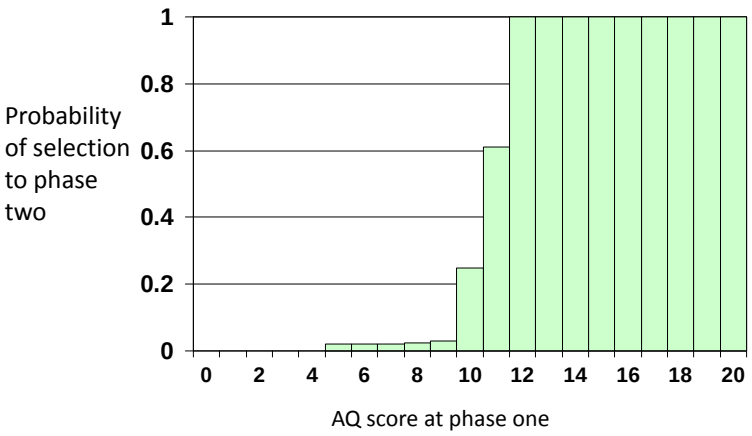
- Review of existing measures
- 50 item Autism-Spectrum Quotient (Baron-Cohen et al)
- Traits
- Validated only in specific populations (Clinic cases vs non ASD controls [samples with little uncertainty])
- Self-report (the only available option in adult surveys)

- AQ-20 subset of Autism-Spectrum Quotient.

Methods

- Range of sampling probabilities for phase two
- Prevalence by strata
- Selection probability increased with AQ-20 score
- Low threshold for eligibility to phase two

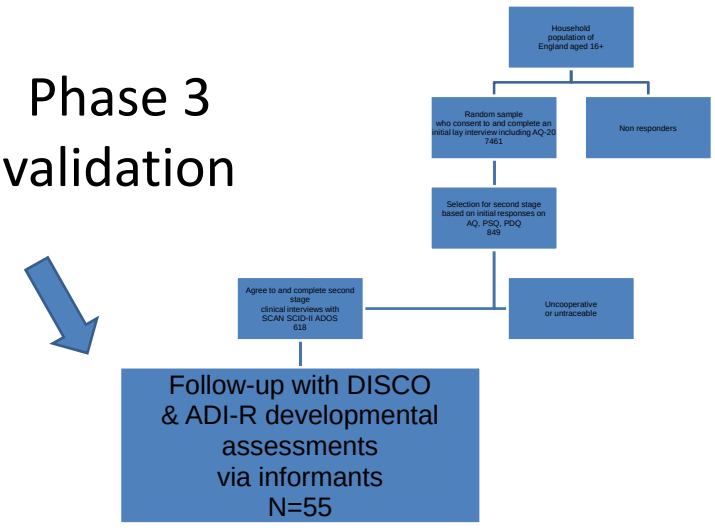
Phase two selection probability by phase one AQ score



Phase two diagnostic assessment in a field work context

- Parents / informants not readily available
- Therefore requirement for a direct 'face to face' assessment of autism in field work interviews:
  - Autism Diagnostic Observation Schedule (Lord et al) Module 4 (ADOS-4)
- Adapting the Autism diagnostic observation schedule (ADOS -4) for the 'normal' adult world – training a team to assess > 600 adults

Phase 3 validation



Calibration of ADOS-4 (phase 3)

- In phase three challenge of finding parents or carers to complete the informant based Diagnostic Interview for Social and Communication Disorders (DISCO) and ADI-R to assess childhood and current development
  1. ADI-R and DISCO used to calibrate primary diagnostic assessment (ADOS-4)
  2. Clinical case vignette rating by experienced professional diagnosticians (Psychol Med, 2011)
- ADOS-4 10+ threshold confirmed for definite ASD

Phase two assessment yield

- 618 ADOS assessments conducted at phase two
- 19 cases of ASD were diagnosed
- 5 of these had an AQ-20 score of less than 10
- **Weighting** corrects for sampling and non-response
- ~72 estimated cases overall (would have been found if we could have conducted ADOS diagnostic assessments on all phase one respondents – i.e. totally impractical)

Performance of AQ-20 screen and ADOS assessment

Best combination of sensitivity and specificity (%)

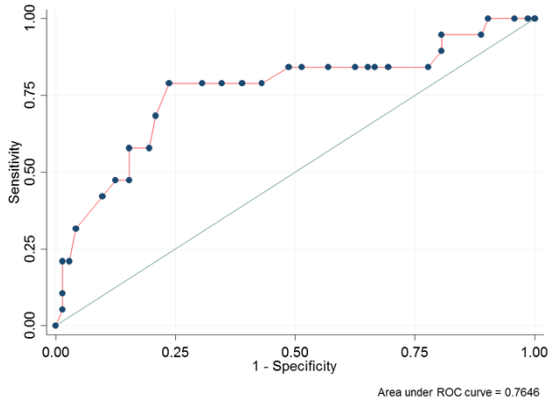
- 10+ AQ-20 cut off (to predict ADOS 10+)
- Sensitivity = 73.7 %
- Specificity = 62.0 %
- Sum = 135.7 %

- McNamee argues for minimum sum of the percentages of 160+ %

Identifying autism in adults in contact with mental health services

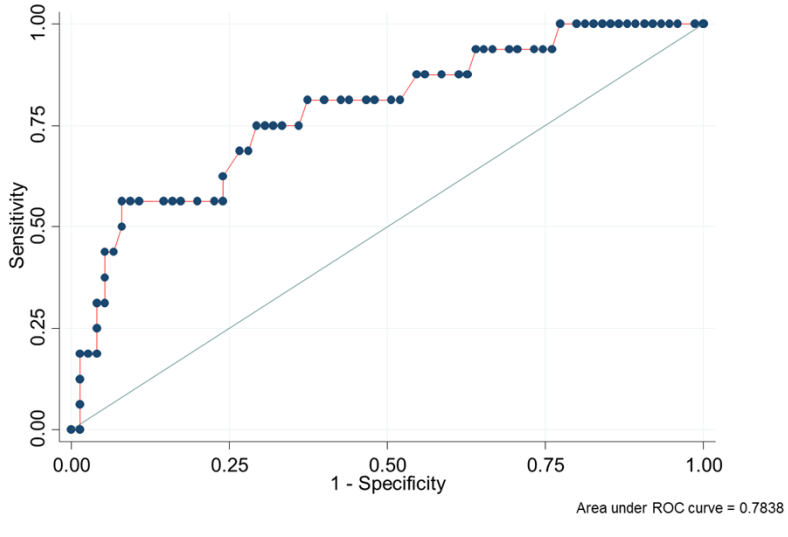
- 50 item Autism Quotient
- RAADS-R questionnaire (self administered)
- Sampling throughout Leicestershire and Northampton shire services

Figure 3.3. The receiver operating characteristic curve for the Autism-Spectrum Quotient (AQ) as a screening tool for autism among adult mental health service users



Optimal sensitivity and specificity for our purposes (highest sensitivity for specificity of 0.70 or above) was achieved at a cutoff of 31. Sensitivity was 0.79 and specificity was 0.76 at this cutoff.

Figure 3.6. The receiver operating characteristic curve (ROC) for the Ritvo Autism-Asperger's Diagnostic Scale – Revised (RAADS-R) as a screening tool for autism among adult mental health service users



Best predictors

- RAADS-R
  - When best 13 items were combined, ROC analysis revealed an area under the ROC curve of 0.88, denoting good diagnostic accuracy. A score of 20+ for these 13 questions revealed a sensitivity of 0.81 (95% CI = 0.54 to 0.95) and 0.72 specificity (95% CI = 0.60 to 0.81). Combined is 153.
- AQ
  - When 8 best items were combined, ROC analysis revealed an area under the ROC curve of 0.90, denoting excellent diagnostic accuracy. A score of 6+ for these eight questions revealed a sensitivity of 0.83 (95% CI = 0.60 to 0.96) and 0.84 specificity (95% CI = 0.69 to 0.89). Combined is 167.

Findings: suitable for a two-phase design

- Sensitivity and specificity differ across populations (as does positive and negative predictive value).
- For the purposes of adult general population survyes, in lieu of a better lay instrument...
- A two-phase survey design with
- a low AQ score threshold for eligibility to phase two
- multiple sampling fractions
- inclusion of everyone with a high score

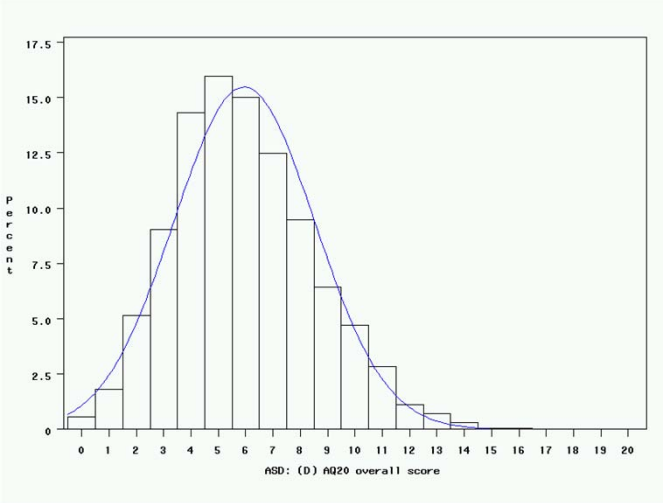
was appropriate.

- This method was used again in 2014.

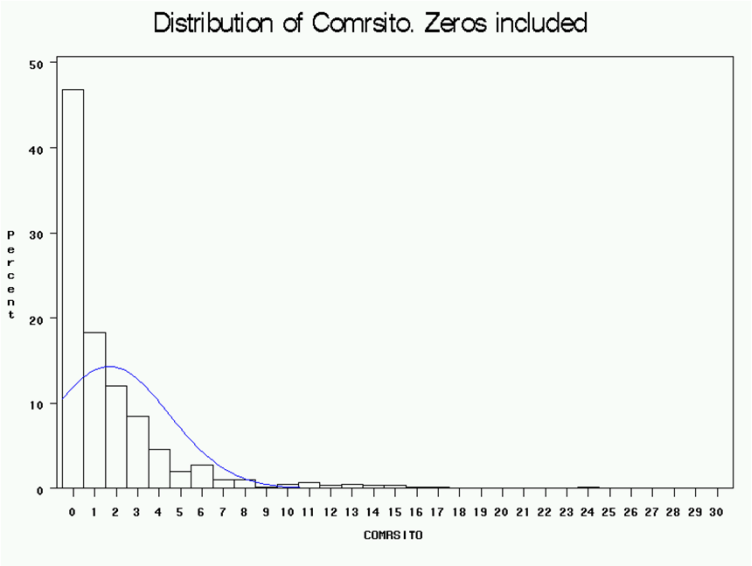
Adult Household Findings

- Distribution of traits and of the disorder in the adult population
- Prevalence according to a range of thresholds
- Associations with ASD in the community

Distribution of phase I AQ-20 scores, ~ 7,400 adults



Distribution of ADOS Scores. Diagnostic threshold 10 or more

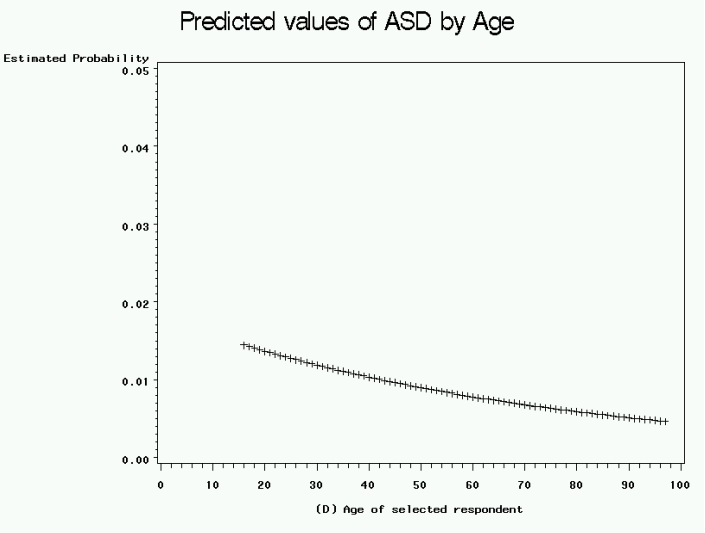


Unweighted and weighted estimates numbers of respondents per 1000 population for ADOS cut-offs from 7+ to 12+ including estimated prevalence of ASD at the recommended threshold of ADOS 10+

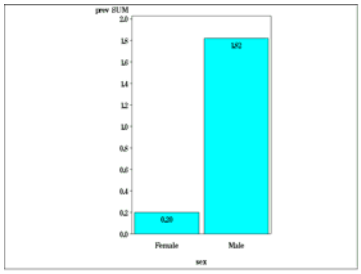
ADOS cut-off	Unweighted Number Base = 2828	Weighted Number Base = 7333	Weighted estimate (95% CI)
7+	32	108	14.7 (7.0, 22.5)
8+	26	88	12.0 (4.9, 19.1)
9+	20	75	10.2 (3.4, 17.0)
***10+**	**19**	**72**	**9.8 (3.0, 16.5)**
11+	16	65	8.9 (2.2, 15.5)
12+	12	47	6.4 (0.6, 12.3)
13+	10	44	6.0 (0.2, 11.8)

Key associations found

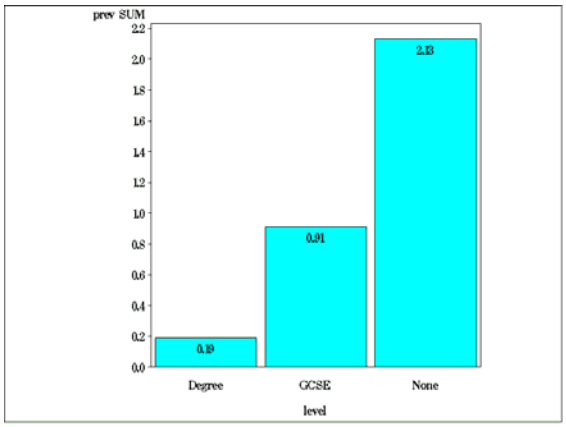
P-value for age as a continuous predictor of ASD (p=0.55) using the recommend threshold of ADOS 10+.



Prevalence by Gender



Prevalence by Educational Achievement



Univariable predictors of presence of Autism Spectrum Disorder (ADOS 10+ N=2,854).

Univariable predictor	Overall P	Comparison	OR (95% CI)	P for comparison
Sex [a]	0.001	Male v Female	9.14 (2.4, 35.2)	0.001
Marital status	0.07	Single v Cohabiting	4.91 (1.2, 19.9)	0.026
		Single v Divorced/separated/widowed	4.27 (1.0, 18.1)	0.049
Tenure	0.002	Social v Owner	11.2 (2.9, 43.5)	0.0005
		Social v Private	5.9 (1.06, 32.3)	0.04
Equivalised household income [b]	0.17	Low v High	5.6 (0.9, 34.6)	0.36
		Low v Moderate	2.3 (0.46, 11.8)	0.31
Highest educational qualification [c]	0.01	None v Degree / HND (College, Uni)	11.6 (2.3, 58.8)	0.003
		None v A-Level / GCSE (school)	2.4 (0.61, 9.18)	0.21
Employment status	0.88	Out of Work v In work	1.86 (0.16, 21.3)	0.62
		Out of work v Inactive	1.55 (0.14, 17.0)	0.72
Receipt of benefits [d]	0.04	Does not know v None	13.3 (1.6, 111.1)	0.02
		Does not Know v Yes	4.67 (0.37, 58.8)	0.23
Index of Multiple Deprivation (IMD) [e]	0.06	High v Medium v Lowest (ordinal)	2.34 (0.96, 5.7)	0.06
NART	0.04	(continuous)	0.94 (0.87, 0.998)	0.04
AGE	0.55	(continuous)	0.99 (0.94, 1.04)	0.55

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NART (Verbal IQ in the range 70-130)	**0.04**	**(continuous)**	**0.94 (0.87, 0.998)**	**0.04**

Key associations found

- Each analysis using the 10+ ADOS threshold was repeated with the 7+ cut-off: the statistically significant associations for gender and tenancy for ADOS 10+ were also found for the 7+ cut-off; those for other associations were also in the same direction but no longer statistically significant.
- As most (15/19) of the discovered phase two ADOS 10+ cases were males, the weighted univariable logistic model (males and females combined) was repeated in males only. The findings were unaltered.

Service contact and use

- Although there were no clearly significant findings ASD cases appeared to be less likely to be using health services for mental health reasons compared with other adults with mental and behavioural disorders
- (note that cases were less likely to know how to answer questions about receipt of welfare benefits)

Combined prevalence of autistic spectrum conditions (ASC) in adults of all ability levels

Traolach (Terry) Brugha
Department of Health Sciences
University of Leicester

Research Team

University of Leicester

Traolach (Terry) Brugha	Professor of Psychiatry / Principal Investigator
Howard Meltzer	Professor of Mental Health & Disability
Jane Smith	Fieldwork Manager
Nicky Spiers	Medical Statistician
Freya Tyrer	Research Manager

Interviewers
Andrew Leaver, Ann Loughnane, Caroline Lovett, Emma Peters, Karen Ricci, Darren Sharpe

Leicestershire Partnership NHS Trust

Sabyasachi Bhaumik	Medical Director
Reza Kiani	Consultant Psychiatrist in Intellectual Disability

University of Glasgow

Sally-Ann Cooper	Professor of Intellectual Disabilities

Autism Research Centre, University of Cambridge

Fiona Scott	Consultant Chartered Psychologist

National Centre for Social Research, London

Sally McManus	Research Director
Susan Purdon	Independent Survey Specialist

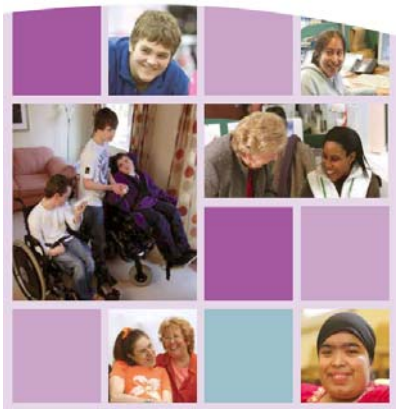
Existing evidence

- Previous household survey (Brugha et al. 2009)
  - 7,400 adults in England
  - 1.0% of adults had autistic spectrum conditions[1]

  However
  - Adults living in communal care establishments (e.g. Residential/Nursing homes) were not sampled
  - People with poor mental capacity could not be screened with the instrument used (*ADOS Module 4 requires sufficient verbal ability*)

1. Brugha et al. (2009). Autism spectrum disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007. England: The NHS Information Centre for health and social care

Population 'missed'



* Valuing People Now. Delivery Plan 2010/11. Department of Health (2010)

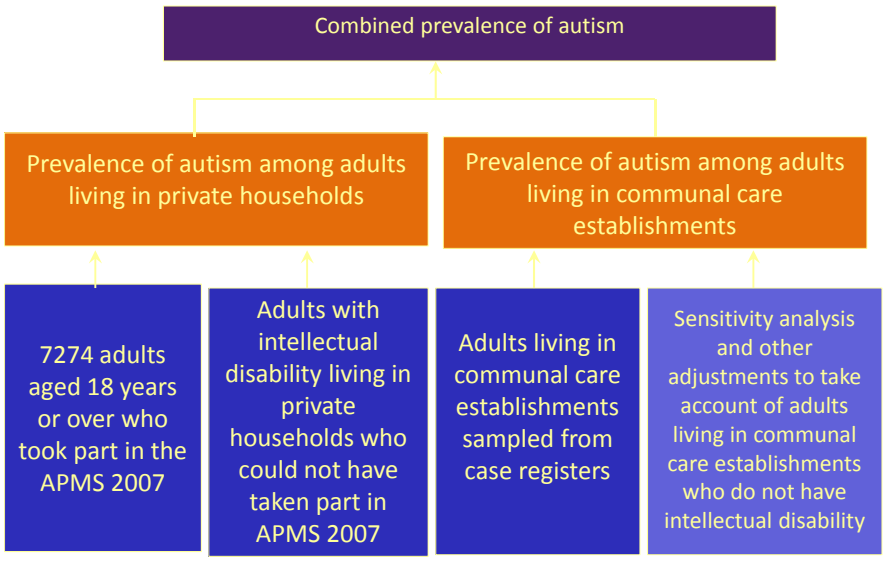
- Survey missed people with intellectual disabilities
  - who make up a significant proportion of people living in communal care establishments and:
  - who will have lacked capacity to take part in the original 2007 survey
- Evidence suggests that prevalence of autistic spectrum conditions higher in people with intellectual disabilities, e.g. Cooper et al. 2007[1]

1. Cooper et al. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry* 190: 27-35

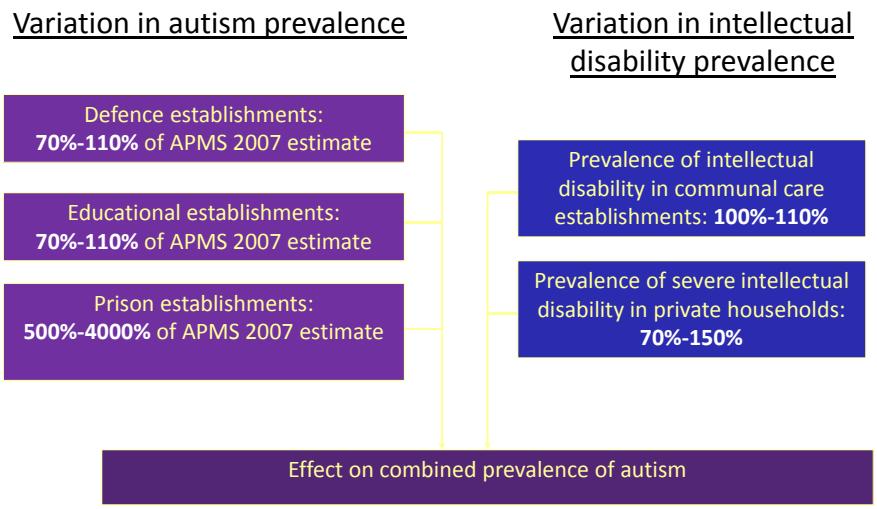
What we aimed to do

- Repeat as far as possible the APMS 2007 in adults with intellectual disabilities:
  - Living in communal care establishments
  - Living in private households
- Combine the results with data from the APMS 2007 to derive an overall prevalence for autistic spectrum conditions in adults in England.
- Use same instruments used in the APMS 2007 where possible

Calculation of autism prevalence



Sensitivity analysis



Study sample for study to extend the APMS 2007

- Adult intellectual disability case registers in England
  - Leicestershire
  - Sheffield
  - Lambeth

Methods: Screening/Diagnostics

APMS 2007	Extension
ADOS Module 4[1] (with participants)	ADOS Module 1[1] (with participants & carer)
DISCO[2] (with informant)	DISCO[2] (with informant)
ADI-R[3] (with informant)	ADI-R[3] (with informant)

1. Lord et al. (2002). The autism diagnostic observations schedule – generic: a standard measure of social and communication deficits associated with the spectrum of autism. *JADD* 30:205-23
2. Lord et al. (1994). Autism Diagnostic Interview – Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *JADD* 24:659-85
3. Wing et al. (2002). The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry* 43:307-25

Sensitivity analysis: Results

- Using assumptions based on different scenarios to account for the prevalence of autism being higher/lower in other settings..
  - the overall prevalence of autism varied between 1.1% and 1.2%.

Results 2: autism by sex, age and ethnic group

- Combined prevalence of autism among men was 2.0% and 0.3% among women.
- Combined prevalence of autism was similar by age group (18-44 years: 1.3%; 45-74 years: 1.1%; 75+ years: 0.6%)
- Combined prevalence of autism was similar in white and south Asian population (1.2% and 0.8% respectively) [*numbers were too small to investigate other ethnic groups*]

Results 1: overall prevalence of autism

- 7274 adults without intellectual disability were included in the APMS 2007.
- 276 adults with intellectual disability were included in the extension study, comprising:
  - 79 adults from private households;
  - 197 adults from communal care establishments.
- **The combined prevalence of autism among all adults was 1.1% (0.3% to 1.9%).**

Key findings on gender

- Adjusted odds ratios for autism by male sex were 1.3 (95% CI 0.5-3.0) for those with moderate to profound intellectual disability,
- - compared to 8.5 (95% CI 2.0-34.9) in those with mild or no intellectual disability, this interaction being statistically significant (p=0.03)
- Therefore the usual male gender excess for autism does not apply to adults with moderate to profound ID
- Only two of many studies in children suggest this.

Why? (and if so, so what...?)

  - Perhaps ...?
- more intellectually able females are more skilled at learning to conceal their autism?
- Autism is missed because it is not expected in women?
- Autism is more misdiagnosed in women (Borderline Personality Disorder; Eating disorder; Depression...)?
  - And if so, then so what...?
- If even more women than men are missed is the overall prevalence of autism under estimated?
- Should the male brain theory of autism be revised?

Summary

- Overall prevalence of autism is 1.1%
- Prevalence is higher in men than women, but does not appear to vary by age
- Prevalence increases with lower verbal IQ / more severe intellectual disability

Public impact

- Initial findings published by the NHS Information Centre, September 2009
- First ever APMS survey to hit the national press and television media
- Hailed as the final nail in the coffin of the MMR vaccination scare
- First ever disability specific act of parliament passed into law two months later in England
- Additional intellectual disability findings ignored...

Methodological challenges

- Assessment in a field work context and calibration
- Reliance on a largely untested first stage screening tool
- Estimating prevalence when the screening tool performs poorly
- The small number of ASD cases found and studying associations with characteristics
- Not possible to model / impute cases at phase one
- But we were able to address the problem of non response and potentially biased estimates

Key discussion points

- If the prevalence of ASD has not changed in the past 70 + years, this suggests that the environmental causes cannot include newly emerging toxins
- Adult ASD is associated with reduced adaptive ability – not genius
- None of the APMS study cases found were 'recognised', which is consistent with a national audit of ASD completed in 2009 – hardly any official recognition (National Audit Office, London)

Adulthood summary

- Unless recognised for the presence of moderate to profound intellectual disability –
- A typical community living adult with ASD is less well educated, unrecognised by health or social care, in poorer housing, living either with family or alone (unmarried), economically disadvantaged (although more than expected were in paid employment)

Diagnosis delayed to adulthood

- Role of psychiatry in triage (comorbidity...)
- Role of GPs in simple problem solving
- Role of social care and other agencies including criminal justice system in alerting to unrecognised need
- More limited post diagnostic treatment evidence base
- Uncertain role of other professionals
- Costs dominated by intellectual disability services

Assessment methods

- No developmental history for older adults
- DISCO and or ADI-R
- ADOS – issues with biased estimation in presence of comorbidities in adulthood
- Direct interviewing...
  - Approaches beginning to be developed
  - Adaptation of WHO SCAN interview to include neurodevelopmental disorders

Adult phenomenology

- SCAN-ND – cross checking with other symptoms
- ADHD, thinking and over-activity
- Repetitive and Rigid behaviours
- Sensory sensitivities
- Social communication, friendship and other relationships
- Reading and revealing emotions
- Adult informants
- Direct observation

Further needs assessment

- Psychology (educational, occupational, neuro)
- Speech and Language
  - Communication
  - Personal Passport
- Occupational Therapy
- Social work
- General (physical) health

Options for intervention

- Value of a diagnosis no matter how late
- Role of remaining carers and their learning
- Social care assessment and checklist for access to welfare benefits and other entitlements
- Reasonable adjustments (next slide)
- Other options

Reasonable adjustments

- Employment
- Access to public services
  - Adjustments by adult psychiatric services
  - Access using text and the web vs telephone/1:1
- Housing
- Disability law and entitlements

Other options

- Pharmacotherapy
- Adaptations of psychological therapies
- Social skills
- Community and psychosocial interventions
- Genetic counselling
- Legal aspects – liberty, culpability, testimony

Other options

- Carer and family support and training
- Other agencies including third sector
- Public policy
  - The Autism Act
  - National Autism Strategy
  - Sharing responsibility across government
  - Education and training
    - General Public (role of media, creative arts...)
    - Professionals (teachers, lawyers, psychiatrists...)
    - Public agency staff (housing, welfare, police, emergency)

Looking forward

- Emerging effective medical treatments
- Backlog of effectiveness research on existing comorbidity treatments
  - Anxiety
  - Depression
  - Psychosis
- Biomarkers and early diagnosis
- Concepts and definitions of what we call autism...

Further reading

- Amaral, D., Dawson, G. & Geschwind, D. H. (2011). Autism spectrum disorders. Oxford University Press: New York.
- Brugha, T. The Psychiatry of Adult Autism and Asperger Syndrome. Oxford University Press: Publication, May, 2018.
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- Tantam, D. (2012). Autism Spectrum Disorder Throughout the Lifespan. Jessica Kingsley: London.

Thank you !

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- http://www.hs.le.ac.uk
- http://www2.le.ac.uk/colleges/medbiopsych

Transition of Autism from childhood to adulthood

Terry (Traolach) Brugha,
University of Leicester,
Adult Psychiatrist and Epidemiologist.

Presentation to Association for Child Neurodevelopmental Disorder, Sweden
13 of March (10.15 -12.00 a.m), Stockholm, Sweden.

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